

Developmental Disabilities Council Outcomes

1999 Highlights



U.S. Department of Health and Human Services
Administration for Children and Families



Dear Colleagues ,

For nearly 30 years the projects and activities of Developmental Disabilities Councils have been national catalysts for improved supports and services for people with developmental disabilities. The Administration on Developmental Disabilities (ADD), in recognizing the importance of this work, has developed this booklet to demonstrate the considerable influence of combined Council efforts, while recognizing the work of individual states.

The numbers and narratives presented in *1999 Highlights* are the results of extensive collaborative efforts and innovative projects and programs of Councils. These outcome measures give us a clear picture of the hundreds of thousands of people with developmental disabilities whose lives have been positively changed through Council efforts. We applaud the excellent results of 1999 and look forward to continued success in 2000.

S. Emerson

Commissioner

Administration on Developmental Disabilities



HIGHLIGHTS OF COUNCIL ACCOMPLISHMENTS IN 1999

The Roadmap to the Future establishes a course of action for the Administration on Developmental Disabilities (ADD) and the programs it funds—Developmental Disabilities Councils, Protection and Advocacy Programs, University Affiliated Programs, and Projects of National Significance. Consistent with the Developmental Disabilities Assistance and Bill of Rights Act (the Act), the Roadmap links program components and ADD to a shared mission and vision of independence, productivity, integration, and inclusion of individuals with developmental disabilities. To attain this mission and vision the Roadmap sets forth goals that fall into six primary goal areas: Employment, Housing, Education, Health, Self-Determination, and Community Inclusion. The goals are common to ADD and each of its programs, and provide a framework for carrying out unique program mandates, implementing diverse strategies and activities, and achieving desired outcomes.

The role of DD Councils in achieving Roadmap goals is to utilize systems change, capacity building, and advocacy activities, to develop and support local and statewide approaches that enable people with developmental disabilities to achieve their maximum potential and participation in the community. In collaboration with the DD Councils, ADD has established outcome measures of systems change, capacity building, and advocacy activities to gauge progress in achieving Roadmap goals.

Captured in these 1999 Highlights are the national aggregate numbers in selected outcome measures along with representative state narratives* for Employment, Housing, Education and Health. Both the numbers and narratives are impressive and representative of the impact and success of DD Council programs.

* Narratives are taken directly from the PPR and are within the 2,000 character limit.



EMPLOYMENT

outcome statement

People obtain and maintain employment consistent with their interests, abilities, and needs.

National aggregate numbers in selected outcome measures

8,959 adults have jobs of their choice

1,113 businesses employed adults with developmental disabilities

16,609 self-advocates and family members were trained in systems advocacy about employment

Alaska Highlights

The Council has carried out a major initiative to address the barriers to employment for people with disabilities. We have completed an inventory of the specific public programs that operate with disincentives for people with disabilities to find and keep jobs, assessed the barriers to employment as perceived by people with disabilities and piloted comprehensive vocational service to include benefits analysis and counseling, vocational futures planning, job development and placement, and ongoing support.

Council efforts resulted in the implementation of the Medicaid Buy-In provision under the Balanced Budget Act 1997. This will potentially benefit 6500 adults with developmental disabilities. Five persons with DD secured jobs of their choice using the pilot program.

An additional four persons started their own businesses as a result of training they received from our project with the UAP and the Alaska Inventors and Entrepreneurs Association. We laid the foundation for a public-private partnership in which small businesses receive small grants in exchange for hiring people with disabilities for five years.



The Council received 224,000 funding from the Rehabilitation Services Administration to integrate work incentives with Job Centers, Alaska's one-stop workforce development program. A think tank involving consumers, family members, advocates, and state agency representatives was convened to establish a five-year work plan to increase employment of Alaskans with disabilities. Staff is working to integrate work plans into the budgets and strategic plans of state agencies.

Pennsylvania Highlights

Over the past several years the PA Council has demonstrated the value of supported employment services and supports for people with developmental disabilities. In viewing our current grant cycle, the Council felt that the focus needed to be on what was happening systemically to support inclusive employment opportunities for people. Two grants have operated over the past 3 years which address systemic issues of employment services funding and delivery. Each grantee was required to work in collaboration with a primary fundor of employment services in their area. One grant focused on providing a voucher program where people could choose and purchase their own employment supports. In collaboration with their County MH/MR program, they provided vouchers that supported 20 individuals with employment in 1999. This project will be ending Council funding in December 1999, but through the continued support of the county program, will be able to continue to offer a similar small voucher program in the coming year.

The second grantee worked with their district Office of Vocational Rehabilitation, local Social Security offices and area corporate partners to provide employment supports as requested & jointly designed with those requesting service. Self directed employment opportunities were provided to 7 people this year. More importantly, perhaps, the corporate partners, Bayer Corporation, US Airways, and PNC Bank began to be actively involved in the hiring practices, and in providing a natural supports approach to employees with disabilities in their companies.

Finally, the Council continued its work in the area of Entrepreneurship, providing training to over 60 OVR counselors on assessing individuals and business plans to assist small business start up. This grantee also published a newsletter geared to the business and commercial lending/banking community regarding successful entrepreneurial efforts involving people who have disabilities.



HOUSING

Outcome Statement

Adults choose where and with whom they live and have services needed to support these choices.

National aggregate numbers in selected outcome measures

34,904 individuals have homes of their choice

Alabama Highlights

The Community Living Initiative assists people with low incomes and/or high service needs. The goal of this project is to provide individually designed financial supports for persons with disabilities who are seeking homes of their own, to increase self-advocates awareness and understanding of community living issues and options through a series of education/training programs, to assist home-seekers in realizing their dream of home ownership or rental and to build statewide capacity in person-centered planning. The project provided development of individual person-centered plans for people wanting the plan. Additionally, direct financial supports to cover items such as closing costs, appraisal costs, rental deposits, and accessibility modifications were provided. Financial education was provided to assist persons with disabilities and families of persons with disabilities with budgeting, resolving credit problems, and preparing for obtaining a home of their choice. The project staff worked with realtors, municipal personnel, government agency staff, bankers, and lenders, as well as social workers, case managers, service agency staff, facility personnel, nurses and counselors to facilitate people with disabilities to obtain homes of their own.

Staff Activities

The Impaired Drivers Trust Fund provides funding, in part, to the Alabama Head Injury Foundation for intakes and casework, resource



identification, medical assistance fund application and advocacy services. Staff served on the Board of Advisors and Housing Subcommittee for this program.

Ohio Highlights

In Ohio approximately 10,000 people with developmental disabilities are living in large congregate settings. These settings include state-operated developmental centers, private ICF/MRs, and nursing facilities. However, there has been a shift in the demand for long-term supports for people with developmental disabilities from congregate settings to settings that will more easily allow for community integration, self-determination, and individual choice. Sufficient resources, experience and expertise are needed to address the needs of those remaining in large congregate settings and to allow them to move successfully into homes of their choice.

In early 1999, the C.H.O.I.C.E.S. project began to assist 25 residents in large congregate settings to make a smooth transition into community living by December 2001. The Arc of Ohio, in collaboration with People First of Ohio and Independent Living Centers throughout Ohio, formed two self-advocacy teams to work with individuals living in congregate settings who have expressed an interest to move into the community. Each team is lead by individuals who are self-advocates and have experience with the system. Team members were trained in relationship building, making choices, and in the services offered by governmental agencies. In addition, other trainings have been completed as needed for team members and persons interested in moving, such as "How to Manage Your Resources" and "How to Advocate for Yourself." Further, team members and persons interested in moving are being supported in the activities necessary to develop friendships and natural supports in the community.

Team members have been matched with individuals identified by Advocacy and Protective Services (APSI), Superintendents of Ohio's Developmental Centers, Local Independent Living Centers, People First of Ohio and private residential providers as interested in moving into the community. Over 50 individuals have been identified.



EDUCATION

Outcome Statement

Students reach their educational goals.

National aggregate numbers in selected outcome measures

609,187 students have the education and support they need to reach their educational goals.

36,928 infants and young children have the services/supports needed to reach developmental goals.

West Virginia Highlights

The Council collaborated with the UAP and other major stakeholders to sponsor and plan the "Impact 2000" initiative and Summer Institute for higher education. The goals of the initiative are to: "infuse" disability issues and content into higher education curricula across non-disability related disciplines; improve the accessibility of campuses by persons with disabilities; increase the opportunities for student practicum placements with persons with developmental disabilities; and increase the opportunities for persons with disabilities and their family members to serve as guest lecturers in schools of medicine and other relevant schools. The "Impact 2000" web site was created (www.uacdd.wvu.edu/impact/). Information was distributed to college faculty and administrators by members of the regional teams, while the steering team coordinates the process statewide.

The Council continued to fund the UAP project "School-Based Positive Behavior Support." Through the comprehensive, statewide positive behavior support system teachers, administrators, community members, families and students with developmental and behavioral disabilities gained skills in how to better support students to become more independent, productive, and included in their schools and communities.



The Council Director and staff continued to develop a collaboration between Head Start providers, the UAP, P & A, and others for improvements in services to children with severe disabilities and delays.

Georgia Highlights

The goals of Project WINS are to establish collaborative implementations of inclusive education processes among network members; to develop regional cadres of training and technical assistance providers to support students with disabilities, their teachers and peers in general education classrooms and schools; and to evaluate the effectiveness of the educational benefits to students and teachers that result from the implementation of research-based inclusive schooling practices.

Activities of the project have included: providing 104 days of technical assistance and site-based training to faculty, staff and parents of the 9 participating schools; hosting and managing a statewide Inclusive Training Institute; and developing partnerships with national organizations such as the American Institute on Research in Education.

Major accomplishments and findings include: students with various disabilities have moved from more restrictive to less restrictive placements at 8 schools; teachers and administrators have reported improved instruction and curriculum integration for all students as a result of training; preliminary IEP data suggest that almost all students performed at least as well and usually better in more inclusive classes than they had in self-contained and resource settings; teachers and administrators from all schools that received actual technical assistance consistently reported that they are better equipped to teach all students in inclusive classrooms as a result of training from Project WINS; and test scores suggest no differences between classes which did and did not include students with disabilities.



HEALTH

Outcome Statement

People are healthy and benefit from the full range of needed health care services.

National aggregate numbers in selected outcome measures

\$823.7 million were leveraged from public and private sources to support health services.

Oregon Highlights

The Council provided training, mentorship and support in organizing for the Medically Fragile Network, a small group of parents of medically fragile children living at home. The group conducted an exhaustive advocacy campaign to persuade legislators to create a fund for in-home care services for medically fragile children. Their efforts netted over a million dollars for that purpose and a promise to revisit the issue next legislative session. The group is also advocating for changes in the way private insurance companies exclude or limit coverage for in-home nursing and equipment. Families are mentoring each other on how to get the most from their insurance companies.

The Council has family and self-advocate representatives on several oversight committees that monitor health and safety of people in ICF/MRs. Those include an abuse and neglect committee, human rights committee, and the State Training Center Review Board. As mentioned in section A, we are also monitoring the health and safety of people who recently moved from an ICF/MR through the Quality Assurance Visitors Project.



Florida Highlights

The Telehealth/Telemedicine demonstration pilot of video teleconferencing between 15 statewide Childrens' Medical Services offices and 80 parents of children with special health care needs enhanced case management, support and family training and education, and provided these services to remote locations in the state.

The Unmet Needs-Health Care Utilization project gathered qualitative, quantitative and instrumental support data on 82 individuals with developmental disabilities living in the community. It began developing a model of support on health care utilization and cost. This research and model can be used to capture prevalence data inclusive of health service needs for persons with DD.

The Families as Teachers project bridges the gap of knowledge, understanding, sensitivity and communications between health care providers and individuals with DD and their families. It has provided training by families to over 1280 pediatric residents and others in the healthcare field, training 6 times more people than projected. A leading health care outreach organization individually funded an additional \$1000 to train their employees.

6,000 copies of Coping with Disability-Related Stress were printed/distributed. The pamphlet lays out related stress and special issues affecting individuals with DD, provides signs that can trigger stress, and guidelines for management, adjustment and coping. It also provides tips and tools and a list of additional resources.

The Medication Monitoring Project has met and exceeded goals by developing the following: 1) Consultant Pharmacist Protocol; 2) Plan for Medication Review Funding; 3) Support Coordinator Guideline; and 4) a small pilot project of individuals in the community.

